# *LOS ANGELES COUNTY COMMISSION ON HIV*

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*While not required of meeting participants, signing-in constitutes public notice of attendance. Presence at meetings is recorded solely based on sign-in sheets, and not signing-in constitutes absence for Commission members. Only members of the Commission on HIV Health Services are accorded voting privileges, thus Commissioners who have not signed in cannot vote. Sign-in sheets are available upon request*

## COMMISSION ON HIV MEETING MINUTES
**November 9, 2006**


| MEMBERS PRESENT | MEMBERS PRESENT *(cont.)* | PUBLIC *(cont.)* | OAPP STAFF |
|---|---|---|---|
| Carla Bailey, *Co-Chair* | Gilbert Varela | Arissa Gabe | Chi-Wai Au |
| Anthony Braswell, *Co-Chair* | Kathy Watt | Francis Green | Kyle Baker |
| Al Ballesteros | Jocelyn Woodward | Shawn Griffin | Angela Boger |
| Cheryl Barrit | Fariba Younai | Miki Jackson | Maxine Franklin |
| Carrie Broadus | | Danny Jenkins | Michael Green |
| Robert Butler | | Mike Johnson | Terina Keresoma |
| Mario Chavez | **MEMBERS ABSENT** | Karly Katona | John Mesta |
| Alicia Crews-Rhoden/Precious Jackson | | Lee Kochems | True Pawluck |
| Hugo Farias | Ruben Acosta | Gabriela Leon | Will Strain |
| Douglas Frye | Daisy Aguirre | Phoebe Liu | Gloria Traylor-Young |
| David Giugni | Whitney Engeran | Richard Martinez | Juhua Wu |
| Jeffrey Goodman | William Fuentes | Stacy Mungo | |
| John Griggs | Elizabeth Gomez | Tabatha Onellette | |
| Richard Hamilton | Jonathan Stockton | Jose Paredas | **COMMISSION STAFF/CONSULTANTS** |
| Jan King | | Nicholas Rocca | |
| Brad Land/Dean Page | | Jill Rotenberg | Virginia Bonila |
| Anna Long | **PUBLIC** | Rachel Russell | Miguel Fernandez |
| Davyd McCoy | | Natalie Sanchez | Emily Gantz McKay |
| Ruel Nolledo | Nicole Argantine | John Saparo | Jane Nachazel |
| Quentin O'Brien | Jeannie Biniek | Negar Sapiv | Khanh Nguyen |
| Everardo Orozco | Cinderella Barrios-Cernik | Tania Trillo | Glenda Pinney |
| Angélica Palmeros | Diana Baumbauer | Rose Veniegas | Doris Reed |
| Gloria Pérez/Terry Goddard | Phillip Chen | Chril Ville | James Stewart |
| Mario Pérez | Mark Davis | Jan Wise | Craig Vincent-Jones |
| Wendy Schwartz | Adrienne Devine | Patricia Woody | Nicole Werner |
| James Skinner | Susan Forrest | Tamar Wyte | |
| Peg Taylor | Idabelle Fosse | Roberta Young | |

1. **REGISTRATION/WELCOME**

2. **CALL TO ORDER**: Mr. Braswell called the meeting to order at 8:50 am.
   **A. Roll Call**: Mr. Vincent-Jones called the role and confirmed quorum.

3. **APPROVAL OF AGENDA**: Mr. Vincent-Jones announced that Los Angeles County Supervisor Zev Yaroslavsky would address the meeting between 12:00 and 12:15, slightly postponing the lunch recess.
   **MOTION #1**: Approve the Agenda Order with adjustment ***(Passed by Consensus)***.

4. **REVIEW OF ACCOMPLISHMENTS**: Mr. Braswell noted the roster of Commission accomplishments in the packet, grouped by committee, and called special attention to several. He added that anyone who would like to add to the list should let Mr. Vincent-Jones know.

5. **GREETINGS**:
   - **A. HIV/AIDS Bureau (HAB) Dialogue**:
     - Douglas Morgan, Director of HIV/AIDS Bureau (HAB)'s Division of Service Systems (DSS) Lorenzo Taylor, the Title I Project Officer for Los Angeles County, joined the meeting to talk with the group by telephone from Washington, DC. Mr. Morgan emphasized the importance of moving people into care. He noted that while Reauthorization is pending, the Bureau continues to operate under current legislative language, and expects to begin using HIV disease data in the funding formula in FY 2007. He emphasized the focus on core services, referring to the requirement in proposed Reauthorization language that programs spend 75% of their funds on these services, including primary medical care, medications, mental health, substance abuse treatment, oral health, and case management services. He acknowledged the challenges faced by Planning Councils in an era of flat or reduced funding. In bringing people into care, many EMAs are finding that to meet the most critical needs of more people, they must offer fewer services. Mr. Morgan responded to several questions:
       - ⇨ **Case Management:** Mr. Braswell asked whether the types of case management now funded are likely to be consistent with Medical Case Management in the proposed Reauthorization legislation. Mr. Morgan replied that in the absence of management review of final legislation, he cannot provide a definitive response. However, he suggested that the Commission might look at the specific meaning of Medical Case Management under Medicaid.
       - ⇨ **Severity Of Need (SON) Index:** Mr. Land asked about federal development of a SON quantitative measure index. He expressed concern that an EMA might be penalized with a lower need index because local and/or state governments contribute to HIV/AIDS services. Mr. Morgan reported that the concept of a quantitative index to measure severe need came from one of the Institute of Medicine (IOM) reports called for in the year 2000 amendments to the CARE Act. He noted that a consultative process has been under way for more than a year. Four national panels continue to review variables. The severity of need issue has been focused on Title II in the most recent Reauthorization proposal. Title I discussions have refocused the issue to "demonstrated need," with somewhat different factors. Transition to a SON index will not take place until an acceptable methodology has been developed, probably in 2010 or 2011. He added that there was clear sentiment on the SON panels not to penalize grantees for allocating local resources to HIV/AIDS care.
       - ⇨ **Capacity Building and Capacity Development:** Ms. Broadus requested definitions, goals and objectives for capacity building and capacity development. Mr. Morgan responded that the emphasis for Minority AIDS Initiative (MAI) is on minority-focused providers, with the intent to increase their client capacity, third-party billing, and improve administrative measures. He added that the guidance and HRSA/HAB website contain more detail. Reauthorization may also result in changes, e.g., capacity building may receive fewer resources consequent to limited funding. Planning Councils need to weigh the need for such efforts against other pressing service needs.
       - ⇨ **Medicaid:** Mr. O'Brien asked about the potential for integration with other parts of CMS like Medicaid and Medicare. Mr. Morgan pointed out significant efforts to integrate changes to Medicare, especially regarding Part D, into provision of medication through ADAP. HRSA as a whole, he continued, was reviewing the implications that the Deficit Reduction Act (DRA) on Medicaid would have on HRSA programs overall. The DRA provides a great deal of new Medicaid flexibility. Changes that previously required a waiver now only need to be included in a state plan. From July 1 forward, for example, states need to be able to demonstrate that people are citizens, people can be charged for emergency room care, and there are increased co-pays and deductibles. The benefits package is changing. HRSA is looking at the impact on all safety net programs, including the CARE Act, and will offer technical assistance to help grantees deal with those changes. Both increased and decreased Medicaid reimbursements are possible.
   - **B. Los Angeles County Supervisor Zev Yaroslavsky**:
     - Supervisor Yaroslavsky thanked all for addressing the challenge of HIV/AIDS in Los Angeles County. Health care is the most important issue in this society, he said, noting that almost 20% of people have no insurance. Even some who are eligible in LA County have not enrolled—though there is a great effort to reach them. He expressed support for a national system that would one day cover all.
     - He was in a public policy position 25 years ago when the first cases of AIDS were reported. He said that made him keenly aware of opportunities missed by people from across the political spectrum then, so he is dedicated to swift action on today's issues.

- Supervisor Yaroslavsky noted that infrastructure to provide any service to those in need takes time to develop and is targeted to the known demographic at the start of the process. Unfortunately, the demographic may change while the infrastructure is being built, so that it may not speak to the people in need once it is completed.
- He pointed out that the infrastructure developed over the last 25 years for HIV/AIDS was focused mostly toward white, gay males who, at the outset, dominated the demographic. Now, however, the demographic has dramatically shifted toward people of color, both men and women. Keeping up with such shifts is a key challenge.
- There must be innovative ways, he challenged, to reach those in need, both those who meet the government definition and those who do not. Otherwise, he stated, services will always be behind the curve of infection.
- Men and women in the African-American and Latino communities have the fastest rate of infection, he pointed out, and it is critical to meet those needs in the communities where they exist. It is critical to be as accessible as public libraries, for example, are.
- The public-private partnership has expanded accessibility by increasing clinics from 39 to 100. With a population of 10 million people, however, that is inadequate.
- LA County moves to "unified command" when there is a natural disaster like a fire, he noted. Under that structure, companies from other areas submit their usual command structures and their agendas to the unified one. He advocated using the same approach for HIV/AIDS in LA County where there are 2,000 new cases a year.
- In disasters, resources are shifted to the worst hit areas, even though other areas may temporarily have less, as everyone works together to achieve an overarching common goal. Supervisor Yaroslavsky encouraged dialogue and partnerships for HIV/AIDS in the same vein, across political, cultural, racial, religious, geographic and agency differences to pool resources in jointly addressing core health issues.
- It also means taking risks to innovate: for example, the current controversy about public service advertising. He noted that England, France, Spain and Latin America use public service approaches that would be X-rated in a movie here but grab attention. These can readily be adapted.
- Supervisor Yaroslavsky introduced his Health Deputy, Carol Kim, and reminded everyone that his office was always open to new partnerships, new ideas and every form of feedback in standing up to the HIV/AIDS battle.

**6. COMMISSION BUSINESS**:

**A. Membership Nominations**:

- Ms. Baumbauer, Director, Family AIDS Network, was nominated for the Title IV seat. She said she has a background in housing and child advocacy.
- James Smith was nominated for the SPA #1, Consumer, Alternate seat. Mr. Griggs said he is very active in the Antelope Valley.

**MOTION #2**: Nomination of Diane Baumbauer to the Title IV seat and James Smith to the Alternate, SPA #1 Unaffiliated Consumer seat for appointment by the Board of Supervisors ***(Passed by Consensus)***.

**B. Case Management, Home-Based**: Ms. Palmeros presented the final standard of care for approval. No public comments were received on this standard.

**MOTION #3**: Approve the Case Management, Home-Based standards of care, as presented ***(Passed by Consensus)***.

**7. PUBLIC COMMENT, NON-AGENDIZED**:

- Ms. Wise, Didi Hirsch Clinic, invited all to the HIV Drug and Alcohol Task Force December 6th "Network and Nosh". The event is being sponsored to encourage collaboration among related services like substance abuse and mental health.
- Ms. Trio, Pals for Health, noted they are the only nonprofit organization in Los Angeles County providing health care interpretation, translation (verbal and written) and training services. OAPP also funds them to train HIV service providers.

**8. COMMISSION COMMENT, NON-AGENDIZED**:

- Mr. Chen, Health Deputy for Supervisor Michael Antonovich, was introduced. He thanked everyone for the Commission's dedicated work and its collaboration with OAPP. He thanked Mr. Perez as well for stressing the importance of collaboration between the two. He also thanked Mr. Vincent-Jones for his assistance with motions and related materials. He thanked Mr. Land and Mr. Griggs for helping him become familiar with HIV and the providers.

**9. ORGANIZING RESPONSE TO UNMET NEED**: The focus of the remainder of the Annual Meeting was how best to assess and address the unmet need for HIV-related primary medical care among people in Los Angeles County who know they are HIV-positive but are not receiving regular medical care. The Los Angeles Eligible Metropolitan Area (EMA) requested technical assistance (TA) through its Project Officer, Lorenzo Taylor, from the Unmet Need TA Center of the Ryan White Technical Assistance Contract (TAC). The TAC assigned Emily Gantz McKay, President of Mosaica—a firm that runs the Unmet Need TA Center—to assist the EMA. Emily helped plan the meeting, provided materials, and facilitated most of the day.

**A. Ensuring a Common Understanding of Unmet Need**: In order to assess and address unmet need, stakeholders need a common understanding of unmet need.

**B. The Commission's Role in Assessing/Addressing Unmet Need**: As the Title I Planning Council for the Los Angeles EMA, the Commission has several specific legislative requirements and some additional HRSA/HAB expectations to meet in relation to unmet need.

**C. Agreeing on Methods to Assess Unmet Need**: In order to address unmet need, the Commission needs first to know who is out-of-care, where these people living with HIV and AIDS (PLWH/A) are concentrated, what their service needs and gaps are, and what barriers may be causing them to be out-of-care. This requires carrying out specific needs assessment efforts.

**D. Agreeing on Strategies to Address Unmet Need:** The EMA can use many different strategies to address unmet need – to find people not in care and help them enter and remain in care. The Commission needs to be familiar with actions it can take in relation to its decision-making, particularly regarding priority-setting, resource allocations, development of directives or guidance to the grantee on how best to meet these priorities, and refining the system of care.

**E. Determining Each Committee's Role in Assessing/Addressing Unmet Need**: Each Committee has a role to play in assessing and addressing unmet need. It is important that committees agree on their roles and ensure coordination of effort so that the Commission is able to assess unmet need and make data-based decisions about how best to address unmet need.

**F. Developing an Unmet Need Work Plan**: The Commission needs a work plan to address unmet need in a coordinated way. A good way to develop such a plan is for each of the Committees to develop its own work plan, and then build on those plans.

**G. Getting Started**: **Identified Concerns**

- Frequently identified concerns include the following. It will be challenging to figure out how to make the best possible use of available resources to ensure "the greatest good for the greatest number." The Commission will have to make some difficult decisions in allocating limited resources. This is partly a question of "political will."
- It is not clear whether the system is prepared to meet the needs of the people currently not in care, if these plans will be successful in helping them to enter care.
- People need supportive services to stay in care – but a focus on unmet need means spending more money on the six core services, which means less Title I funds will be available for supportive services.
- A key question for the Commission is: what resources is it willing to invest in addressing unmet need? Is it going to get a return on that investment? The Commission will have to spend money and effort to be sure it is done appropriately.
- It is not really known to what extent people not in care are out-of-care because they face barriers like co-morbidities, or because they choose not to enter care. However, all PLWH/A should have the opportunity to obtain care if they want it.
- OAPP, as well as the Commission, faces challenges. The Commission needs to make decisions and plan for addressing unmet need; the grantee responsibility is to try to meet the needs of everyone eligible for care.
- Given flat or reduced Title I funding, the EMA needs to figure out how to leverage other funding sources.
- It is not fully understood how deep the impact of HIV/AIDS is in areas that are hard to penetrate. The Commission needs to measure this impact, and to identify barriers to care. Clearly, there are geographic disparities in service access. Helping people enter care will probably require an aggressive case-finding effort.
- Social stigma plays an important role in unmet need; destigmatization might lead to more people entering care.
- To address unmet need, the participants must recognize, understand, and address the traditional unequal access to care among communities of color and the impact of racism. A part of this is ensuring that services are culturally competent.
- It is important to identify other resources and providers, not just those providing HIV-specific services. Stakeholders talk about a system of care, but there is often a "disconnect" with non-Ryan White and non-AIDS-funded providers.

**H. Getting Started: Identified Challenges**

- How to define the need – both human and care aspects.
- How to effectively calculate and assess who is out-of-care.
- How to engage people in treatment and retain them in care -- which requires identifying successful strategies to bring people into care, as well as ways people get failed by the current system of care, and changing the system of care so it serves people better.
- How to identify and bring into care members of hard-to-reach populations, including new and emerging groups (many of them people of color), people who are unwilling to disclose their status, and people with co-morbidities.
- How to address cultural issues and long-standing limitations on access to health care for people of color.
- How to deal with different parts of this very large county – all eight SPAs.
- What to do around PLWH/A education and with promotion of services.
- How to develop a sound plan, fulfill the plan that is developed, avoid having a plan that is "etched in stone," and instead have one that is flexible and can be adjusted as the situation changes.

- One participant emphasized that there are three categories of knowledge to take into account in assessing and addressing unmet need: 1) things we know we know, 2) things we know we don't know, and 3) things we don't know we don't know.

**10. OVERVIEW OF PLANNING COUNCIL RESPONSIBILITIES FOR ASSESSING/ADDRESSING UNMET NEED**:

**A. Defining "Unmet Need"**: Ms. McKay provided the HRSA/HAB definition of "unmet need": the unmet need for HIV-related primary medical care among individuals who know their status but are not in care. The estimate of unmet need is the number of people living with HIV and AIDS in Los Angeles County who know they are HIV-positive but are not receiving HIV-related medical care.

**B. Legislative Responsibilities and HRSA Expectations**: Ms. McKay explained that the 2000 CARE Act Amendments require the Department of Health and Human Services to provide a national estimate of unmet need. The amendments also required each Title I and Title II grantee to assess service needs and gaps with particular attention to individuals who are not in care.

**C. Estimating Unmet Need**:

- Ms. McKay noted that the grantee has primary responsibility for estimating unmet need, using an Unmet Need Framework provided by HRSA/HAB.
- The working definition of unmet need for this estimate uses a very limited concept of what it means to be "in care." A person is considered to be "out-of-care" if there is no evidence that s/he received any of the following during a defined 12-month period: a viral load test, a CD4 count, or provision of anti-retroviral therapy. This means that a PLWH/A with any of these tests/treatments less than 12 months before is considered to be "in care" for purposes of the estimate. This does not mean that the individual is getting care that meets Public Health Services or EMA standards for good quality care – it measures that there is evidence of some basic components of primary care that can be obtained from public and private databases, including claims databases like Medicaid.
- Participants reviewed the most recent estimate of unmet need for Los Angeles County, which is based on calendar year 2004 data. As of the end of 2004, an estimated 46,000 people in the County had HIV or AIDS and were aware of their status. Almost 31,000 of those who knew they were HIV-positive were a part of the CARE Act system, and received primary care either within that system or through other entities. However, more than 15,000 people living with HIV in the County were believed to have an unmet need for HIV-related primary medical care. An estimated 30% of PLWA, 37% of PLWH, and 33% of PLWH/A were out-of-care.
- The estimated unmet need in Los Angeles is somewhat lower than the estimate for all Title I programs and considerably lower than the estimate for all states.
- The estimate does not distinguish different categories of people who are not in care. However, Ms. McKay identified four different categories of people with unmet need: 1) newly diagnosed; 2) receiving some HIV-related services (and often in the CARE Act system), but not in primary medical care; 3) formerly in care – dropped out (and known to primary care providers); and 4) never in care. The last group is the hardest to find. All other groups are known to entities within the HIV prevention or care system.

**D. Assessing Unmet Need**: Ms. McKay noted that assessing unmet need is primarily a Planning Council responsibility, and is a special part of the Commission's legislative responsibility for needs assessment.

**E. Addressing Unmet Need**:

- Ms. McKay explained that addressing unmet need is a shared responsibility of the Commission, OAPP, providers, and consumers.
- The special responsibility of the Commission is to use information on unmet need in planning and decision-making about how to address unmet need, which includes providing guidance to OAPP as part of the priority-setting and resource allocations process.

**F. Issues and Challenges**:

- The Commission identified a number of issues and challenges in the introductory activity. They make it clear that estimating, assessing, and addressing unmet need requires difficult decisions.
- Ms. McKay noted that perhaps the greatest challenge with unmet need is that it requires changes in both thinking and action for the Commission – a new way of thinking about service gaps, new ways of doing needs assessment, and new information to consider in priority-setting and resource allocation.
- Participants indicated that at a time when Title I resources are flat or decreasing in most EMAs, it is particularly challenging to focus on finding people who are not in care and help them enter care – knowing that this means less money will be available for each individual in care.
- However, because medical care and medications are often the difference between life and death, the Commission has a moral as well as a legislative responsibility to address unmet need.

**12. ASSESSING UNMET NEED**:

**A. Purposes—Determine Characteristics, Needs, Gaps and Barriers**:

- Ms. McKay noted that knowing the number of people who are out-of-care is not sufficient information to be able to decide how to address unmet need. Decision-making requires more information about who they are and why they aren't in care.
- Assessing unmet need means determining the characteristics of PLWH/A who are not in care (e.g., race/ethnicity, gender, age, risk factors, co-morbidities), where they live in the EMA, their barriers to care, the mix of services they need, and what subpopulations are most likely to be out-of-care.

**B. Strategies Used in Other EMAs and States**:

- Ms. McKay presented a range of approaches used in other EMAs and States to assess unmet need, including demographic analysis, surveys or interviews (including questions in PLWH/A surveys and special studies targeting people who are not in care), having peer advocates or outreach workers do interviews as part of their ongoing work, and using provider and key informant interviews to gain additional perspectives on barriers and related issues.
- One of the key requirements of assessing unmet need is finding individuals who are not in care and learning about their service gaps and barriers to care. It is much easier to find people who are already in care, so most "PLWH/A surveys" are really "consumer surveys." It is important to talk to people in care, but also important to understand that their service needs and gaps and barriers to care may be very different from those who are not in care. Ms. McKay indicated that to successfully assess unmet need, the Commission will need to:
  - ⇨ Involve CARE Act-funded providers and non-CARE Act-funded providers where people with HIV/AIDS are likely to be found, like homeless shelters, drug treatment centers, and food banks.
  - ⇨ Go to "points of entry" – places where people get tested or referred into care (providers have memoranda of understanding with points of entry because the CARE Act requires it, but some agreements are just on paper and others are real).
  - ⇨ Do interviews – people out-of-care rarely complete self-administered surveys or attend focus groups. You can talk to them in group settings only in pre-formed groups or other settings where they are comfortable, not by advertising the way you do with other focus groups.
  - ⇨ Target populations with high rates of HIV/AIDS – based on your epidemiological data – by location, race/ethnicity, risk factor, etc. It is much easier to find people out-of-care if you know the kinds of people you are looking for.
  - ⇨ Involve PLWH/A, including members of the Commission. Almost everyone knows other people who are not in care. Train them as interviewers.

**C. Brainstorming: LA Assessing Unmet Need**:

- Participants worked in small groups to brainstorm how the Commission should go about assessing unmet need. The group identified numerous approaches for assessing unmet need. Following are approaches that were mentioned by more than one group or considered particularly promising.
- **Surveys/Interview Guides:** There was broad agreement that the Commission needs to develop a survey tool or interview guide specifically designed for use with PLWH/A who are not in care and to use it for a countywide assessment of unmet need. Groups offered many suggestions about how to develop and use the tool, such as the following:
  - ⇨ Tailor the survey questions for each of the four categories of people not in care.
  - ⇨ Use "lenses" including culture, gender, and age.
  - ⇨ Use Service Provider Networks (SPNs) to help with the surveys in all SPAs.
  - ⇨ Ensure that both Ryan White-funded and non-funded service providers are "at the table" and engaged in identifying people out-of-care. This might include conducting a comprehensive survey of providers who offer ancillary services, and asking them to work with their clients to assess unmet need among clients who are not receiving medical care.
  - ⇨ Look for PLWH/A out-of-care, with targeting based on the four categories of people not in care and where each group is most likely to be found.
  - ⇨ Go frequently (not just once) to some key hotspots or gates, such as food banks, detox centers, and emergency shelters, and emergency mental health service providers.
  - ⇨ Target traditionally undeserved communities with known health disparities. Go to non-traditional venues where these communities congregate, such as Latino supermarkets.
  - ⇨ Find a way to contact people who were recently tested and did not go immediately into care. If people sign a consent form when tested, they can be contacted if they do not move into care. Many people need time to adjust to their status, but it is important to maintain contact with them (perhaps through a peer educator or outreach worker) during this period.
  - ⇨ Contact nontraditional medical providers to access PLWH/A who use alternative medicine.

- ⇨ Use HIV-positive individuals to conduct surveys. Also ask them to help find people out-of-care using a "snowball" sampling approach. Participants who are HIV-positive consistently said that PLWH/A almost always have friends and acquaintances who are not in care and can help reach and interview them.
- ⇨ Offer cash incentives to people not in care to be interviewed, and perhaps to interviewers and agencies who locate and interview them.
- ⇨ Be sure to target women of color. They have not traditionally been targeted. Sometimes their partners do not want to be tested or do not want to reveal their status, which raises some complex issues. The Commission needs to figure out where to find and how to approach women of color to ensure that they have access to care. Possible sites include churches, community parks, nail shops, beauty shops, schools and day care centers, and the welfare office. It may be possible to talk to them by going to places where they are comfortable, and not asking them to disclose their status.
- ⇨ Use clinics to target former clients who have fallen out-of-care.
- ⇨ Compare data on individuals who are getting the care they need, those about to be lost to care (e.g., no medical visit or lab work in nine months), and those not in care.
- ⇨ If it is too demanding to target all populations the same year, do this over 2-3 years, targeting different out-of-care populations each year.

- **Mini-surveys:** Participants liked the idea of having a mini-survey on an index card with 7-8 questions that can be filled out year-round as part of outreach and other community activities. They suggested asking many people to complete these mini-surveys in their community work, including peers, *promotoras*, outreach workers, and PLWH/A Commissioners. Prevention personnel might also participate. The completed mini-surveys should be reported and aggregated every 2-3 months.
- **Databases:** Participants identified a number of ways to use existing databases in the assessment of unmet need. For example:
  - ⇨ Use Case Watch to identify people who are in the CARE Act system but have no documentation of having received primary medical care or lab work in the past year. Use the data to obtain demographic profiles of such individuals by SPA.
  - ⇨ Ask case management and other providers to provide demographic information on clients who are not in care; include funded and non-funded providers.
  - ⇨ Establish a system of referrals and data sharing that involves non-CARE Act-funded providers, using "2006 technology" such as an Internet-based system. The database should provide real-time reporting, supporting referrals and building an infrastructure that continually assesses unmet need at the same time is helping the EMA to address unmet need.
  - ⇨ Match HIRS (HIV Information Resource System) testing and Case Watch data, and see who is not in care.
- **Ethnographic studies:** Several groups suggested using some kind of ethnographic study such as the RARE (Rapid Assessment, Response, and Evaluation) approach for better understanding unmet need. One suggestion was to try using professional observers to identify and follow for a day a sampling of clients from each SPA, to understand where and why a client gets lost to the system.
- **Focus groups:** Several groups suggested using focus groups of either PLWH/A not in care or individuals knowledgeable about such populations. Ms. McKay noted that generally, people not in care do not choose to participate in focus groups. The exceptions are existing groups, where people feel comfortable with each other. Several participants suggested doing focus groups in which people very likely to be HIV participate, but are not asked to disclose their HIV status.
- **Passive outreach:** Two groups suggested the use of passive outreach methods. These might involve:
  - ⇨ Establishing an 800 number and an e-mail address that HIV-positive individuals not in care can contact to get surveys. Interview them, and also try to refer them to care.
  - ⇨ Providing flyers that give information on the availability of free health care, with a phone number to call. When the individual calls, do a brief interview and also refer the individual into care.
- **Add-ons to existing surveys:** It was suggested that there may be several existing surveys to which a question might be added. For example, it might be possible to add a question about HIV status to the Los Angels Health Survey, which is conducted regularly, and then oversample that population, to obtain demographic and service information about individuals who are HIV-positive.
- **Public policy changes:** One group emphasized the importance of being able to use surveillance data in assessing unmet need and obtaining demographic profile data on those in and out-of-care. To do this, it is important to have laboratory reporting required as part of the surveillance system, in order to be able to identify individuals in and out-of-care through surveillance data. The group suggested the need to explore public policy options that might lead to the State's requiring laboratory reporting into the HIV/AIDS Reporting System (HARS), especially consistent CD4 reporting between HARS and surveillance.

**D. Key Approaches for Los Angeles**:

- The approaches that were most often identified include:
  - ⇨ A special unmet need survey/interview guide to be used countywide to assess unmet need, with careful targeting of specific populations that are especially likely to be out-of-care and of the four categories of people not in care.
  - ⇨ A mini-survey that can be used year-round to collect basic information about people not in care and their barriers to care.
  - ⇨ Use of existing databases, particularly CaseWatch, to identify people not in care and determine their profiles.
  - ⇨ Involvement of PLWH/A as sources of "snowball" samples identifying people not in care and as interviewers.
  - ⇨ Involvement of both Ryan White-funded and non-funded providers in the assessment of unmet need.
- Several participants emphasized that it is important once you have located someone not in care both to assess unmet need and to try to refer the person into care. It would be very unfortunate to find a person not in care and fail to offer that person both written information on available services and a more direct referral.

**14. ADDRESSING UNMET NEED**:

**A. Purposes: Helping PWLH/A Enter and Remain in Care**:

- Ms. McKay explained that addressing unmet need typically requires a joint effort involving the Planning Council, grantee, providers, prevention groups, and consumers.
- The key responsibility of the Commission involves data-based decision-making to ensure equitable access to care regardless of characteristics or place of residence within the EMA, help PLWH/A get into care, keep them in care, and ensure that supportive services contribute to primary care entry and retention.
- Planning Councils focus their efforts on decision-making around priorities, allocations, directives or guidance to the grantee on models of care and geographic- and population-focused efforts to ensure equal access to care, and improving the system of care. Efforts to refine the system of care often use such means as ensuring that Standards of Care require providers in all service categories to do all they can to help PLWH/A enter primary care, monitor and follow up on referrals to ensure that they get needed services, coordinate services, and follow up on people who miss appointments.
- Comprehensive plans should have goals related to unmet need, to help ensure that it is an ongoing priority.

**B. Range of Strategies Used in Other EMAs and States**:

- Ms. McKay described (and provided handouts on) a variety of strategies being used by other EMAs and States to address unmet need.
- Strategies are often different for the different categories of people not in care and different populations of PLWH/A, and should address identified barriers to care. Typically, some changes are needed in the continuum of care in order to make care accessible and appropriate for different groups of PLWH/A.
- For the recently diagnosed, strategies typically require improved links between prevention and care. For PLWH/A receiving other CARE Act services, strategies need to involve funded providers in all service categories so they can explore which of their clients are not receiving HIV-related primary medical care and help them enter care. Similarly, those who have dropped out-of-care are known to primary care providers (CARE Act-funded and non-funded), who can identify them and work with other providers on follow up. The hardest group to find and help into care is usually those who have never been in care, since they often are dealing with other issues such as homelessness, mental illness, or substance use.
- There was discussion of new approaches to outreach, such as the value of involving PLWH/A who are on disability hired by providers to work a small number of hours a week to do very focused outreach in specific communities.

**C. Current Commission Activities**: The Commission's Executive Director had prepared a presentation on current Commission-related unmet need activities, but it was postponed due to time constraints and will be presented at a future Commission meeting.

**D. Current OAPP Activities**: Dr. Michael Green had prepared a presentation on current OAPP-related unmet need activities, but it was postponed due to time constraints and will be presented at a future Commission meeting.

**E. Identifying Priorities and Strategies**:

- There was discussion of the need to develop strategies appropriate to the different categories of people not in care, and also to focus on PLWH/A subpopulations within Los Angeles County that are especially likely to be out-of-care, such as women of color and youth.
- Some of the same techniques used to locate people to assess their service barriers and gaps can be used to find them to assist them in entering care.
- In Los Angeles County, surveillance does not contact people after testing except in very unusual circumstances, and partner notification is done by a different County agency, when done at all. This makes it particularly important to link with newly diagnosed people at testing sites.

- It was agreed that the Commission needs to develop its own "marching orders," and implement a "new paradigm" that makes unmet need a continuing consideration in decision-making.

**F. Next Steps**:
- It was agreed that each Committee needs to consider its roles and responsibilities regarding unmet need.
- Once the work of individual Committees has been agreed upon, the Executive Committee and full Commission can ensure that the efforts of all Committees are coordinated and integrated into decision-making.
- The Commission also needs a capacity-development strategy – it needs to look at whether the system can accommodate large numbers of new clients, and figure out how to develop increased capacity. This will mean deciding "what we're not going to fund" to accomplish this, and creating links with non-Ryan White-funded services.
- The group agreed that some investments are going to be needed other than Ryan White, which suggests that a public policy strategy is also a priority.

**16. COMMITTEE ROLES RESPONDING TO UNMENT NEED**:

**A. Making Unmet Need A Part of Committee Work Plans**: The participants divided into Committee-focused small groups to explore how each committee should help in assessing and addressing unmet need. The groups included a combined Finance and Recruitment, Diversity and Bylaws (RD&B) Committee group, and individual Priorities and Planning (P&P), Standards of Care (SOC), and Public Policy Committee groups.

**B. Determining Each Committee's Role**: Each Committee group met, with representatives of OAPP and the public participating, to discuss its role and priorities in helping to assess and address unmet need. Each Committee group then reported to the full group, as described below. The group offered suggestions and comments.

**C. Committee Roles and Priorities**:

- **Combined Finance/Recruitment, Diversity & Bylaws (RD&B) Committees**

**1) Fundraising and fundraising coordination**:
- ⇨ To approach foundations to secure funding for an assessment of unmet need.
- ⇨ To look for funding—possibly from foundations, perhaps from other sources—for service promotion as an intervention to address unmet need.
- ⇨ To serve as a clearinghouse for the Commission for all proposals that might be going out, to ensure coordination and avoid multiple uncoordinated requests to the same funding sources.

**2) Technical analysis**: Determine how much it would cost to bring this unmet need population into care. Use some kind of cost modeling to figure out the cost of providing services to almost 16,000 new clients. For example: look at the total amount of money allocated to medical outpatient services and determine the cost per patient and cost per visit, then look at other EMAs for models of efficiency. Use that as a benchmark and see if other entities around the country do it more efficiently. If there are more efficient mechanisms, or if it's determined that the money is used efficiently, and the Committee can determine how much it is going to cost to provide services to bring a specified number of people into care, then there is an argument for X more dollars to provide those services. Then groups can start working collectively to advocate for those more dollars.

**3) Alternative funding sources**:
- ⇨ Do some assessment this year of what those alternative funding sources are. For example, explore if the EMA funneled mental health dollars from the Ryan White CARE Act through the Department of Mental Health, it might be able to match Medicaid funding, and increase the available services for mental health and HIV.
- ⇨ Determine how much money other agencies currently devote to HIV services. For example, go to Alcohol and Drug Program Administration (ADPA), and find out how much of its budget is devoted to people with HIV/AIDS.
- ⇨ If there are specific interventions other committees/groups are interested in pursuing, model the costs of each intervention. For example, determine the costs of additional case workers to bridge that gap involving people who test positive and don't get into care.

- **Priorities and Planning (P&P) Committee**

**1) Assessing unmet need**:
- ⇨ Use the Service Provider Networks (SPNs) – they represent a mechanism already in place that can be implemented quickly to help in assessing unmet need.
- ⇨ Review and evaluate the Continuum of Care.
- ⇨ Look at the coordination between prevention and care, and Section 8, DPH, DMH, DHS, and HOPWA – look systemwide to develop collaboration with these entities.
- ⇨ Use SPA health officer meetings locally and regionally, which include local providers in those areas, as another opportunity for the SPNs to become more engaged in identifying people out-of-care.

- ⇨ Look at Quality Management and Quality Assessment – start taking a look at some of those systems and support OAPP's enforcement efforts in maximizing service delivery.
- ⇨ As tools are being developed, do the adaptation systemwide, so there aren't so many different tools going out and generating information that cannot be fully utilized.
- ⇨ Develop some kind of appropriate public awareness campaign to overcome the problem that people outside the system really don't know about the system. For example, review the Warm Line.
- ⇨ Replace H-CAP with the collaborative needs assessment, a collaboration of prevention and care, trying to coordinate the annual needs assessment and quality data, and doing redesign of some questions and the continuity of those questions. Coordinate this with the Standards of Care Committee, which will be evaluating service effectiveness.
- ⇨ Work with SPNs to identify the demographics – a number of ways to do it better have been identified.
- ⇨ Work with the SPNs that report who has dropped out-of-care through coordination and reporting, to see if they can capture some of this information locally.
- ⇨ Have CaseWatch run geographic areas, as a starting point in framing some of this data and figuring out what areas and populations to target in addressing unmet need.
- ⇨ Develop an engaging questionnaire addressing dropping out-of-care and coming back into care, and provide for systemwide coordination of the questionnaire.

**2) Priority Actions**:

- ⇨ Technical assistance in April on a System Dynamic Thinking Continuum - Rethinking the Continuum, which will look at the entire continuum of care. Participation requires a commitment of four days over two months.
- ⇨ Prioritize a variety of different linkages, including incarceration and substance abuse services.
- ⇨ Think of incentives provided through use of fee-for-service and how that will work in the system of care.
- ⇨ Work with OAPP to get the HIRS program working,

- **Standards of Care (SOC) Committee**

**1) Rationale**:

- ⇨ Unmet need involves a lot of different aspects of Standards of Care.
- ⇨ The Committee has decided to take one step back and focus on one issue related to how expensive and difficult it is to locate and capture people who have dropped out-of-care: case closure, with emphasis on case management.
- ⇨ The Committee has agreed that in the next revisions of Standards of Care, it will look more closely at case closure.
- ⇨ Case closure provides an opportunity to get more information – e.g., where did the client move to, where are s/he getting care, and is s/he receiving primary medical care?
- ⇨ It is sometimes possible to get some information during transfer of files to another provider.

**2) Why people drop out-of-care**: The Committee identified three tiers of people who leave care, and suggested building an outreach component entailing active follow-up with clients who have missed appointments. The same model also helps provide tiers of case closures and how to address them:

- ⇨ **Tier 1** – Reasons that are not so difficult to address, such as going somewhere else for care. The provider may be able to offer an incentive for them to provide information about reasons for case closure: for clients who provide information about why they are leaving, give them the option of having a copy of their records, so they won't have so much trouble collecting information such as proof of HIV-positive status if they go to another provider.
- ⇨ **Tier 2** – Those who have competing needs and therefore don't show up for appointments. Contact is sometimes made by staff, but might better be made by peers as a kind of outreach component.
- ⇨ **Tier 3** – Those who don't trust or haven't bought into the idea that they need to take care of their disease. Peers may be more successful than other staff in contacting and obtaining information from them.
- ⇨ The group suggested looking at case acuity and how it relates to dropping out-of-care, and it was noted that Case Watch includes information on acuity.

**3) Use of expert panel**: The Committee will convene an expert panel to discuss how Medical Case Management can be an inclusive category. The Committee will add case closure discussion to the agenda, to include what kinds of case closure really work, the appropriate interventions, the utility of 6- and 12-month follow-up, and what kinds of data should be collected.

**4) Standards for case closure**: The group raised the question of what is the appropriate action to take before closing a case: three telephone calls and a letter? something more direct, such as personal contact by a peer outreach worker? The Committee agreed that:

- ⇨ Standards might require some consistent way to follow-up before closing a case.

- ⇨ One approach might be an outreach component using peers.
- ⇨ Standards might call for checking with former clients in six months or one year to get information about their current status with regard to medical care

5) **Other standards issues**: The group noted that all the outcomes currently connected to the standards measure positive outcomes. It might be good to add some negative outcomes that deal with disenrollment.

6) **Other needed actions**:
- ⇨ A form might be developed to capture information on acuity level and dropping out.
- ⇨ An interview form could be used as a Quality Management tool and tied into CaseWatch.
- ⇨ Some people use only medical care, and a mechanism is needed to keep track of them.

- **Public Policy Committee**

1) **Integrating assessment with assessments by other public health programs**: The group wants to see the Commission's assessment of unmet need integrated with existing surveys and assessments of other public health programs, and expects to take the following actions:
- ⇨ Explore partnerships and collaboration with Public Health, beginning with an approach to Dr. Fielding's office. If necessary, obtain some support for his efforts from the Board of Supervisors.
- ⇨ Talk to the Pasadena and Long Beach health departments.

2) **Partnerships with other social services programs**: The group also wants to advocate for a similar type of assessment to be worked into other social services programs, as a valuable source of data. While many municipalities in Los Angeles County, including the City of Los Angeles, do not have health departments, many have social services-related programs.

3) **Dissemination of needs assessment data**: Often, needs assessments are done but not really disseminated; the information does not get back to the community. The Public Policy Committee sees a role for itself in making sure that that information the Commission gathers and analyzes is disseminated to the community for use at a more micro-level.

4) **Links with private entities**: The group will consider advocating for increased collaboration and data sharing with private entities. For example, the EMA could improve its estimate of unmet need if it could obtain data on PLWH/A in care from Kaiser-Permanente. Such information is being provided by Kaiser in Northern California, but not yet in Southern California. Such collaboration can support both estimation and assessment of unmet need.

5) **Recommendation to Standards of Care**: The group recommended to the Standards of Care (SOC) Committee that it incorporate in the Standards for support services a requirement that providers make referrals to primary care if they identify clients who are not in care.

6) **Timeline**: The group indicated that they would adopt and or flesh out ideas at the Committee's November meeting and work out action steps and a timeline. The Committee expects to spend 3-6 months developing proposals and scheduling appropriate meetings for the specified actions.

**17**. **PLAN OF ACTION**:

**A. Areas of Agreement on Assessing/Addressing Unmet Need**:
- Assessing and addressing unmet need will be an important, ongoing role for the Commission.
- The Commission needs to know more about people who are out-of-care – who and where they are.
- The Commission should integrate unmet need considerations into its ongoing work, including the work of the Committees.
- The Commission will coordinate with OAPP in both assessing and addressing unmet need.
- There is a need for greater coordination with the Prevention Planning Committee and with prevention programs. Such collaboration is needed for both assessing and addressing unmet need.

**B. Structuring and Coordinating Efforts**:
- Each Committee will go back and further develop its work plan around unmet need.
- The Commission will receive reports from all Committees.
- Committees will consult with each other on work involving more than one Committee.
- The Finance Committee will serve as the clearinghouse for all Committees regarding securing other resources.
- SOC will continue to be the point of contact with Quality Management and the Quality Management Steering Committee.

**C. Work Planning**: **Tasks, Responsibilities, Timeline**: Each Committee will use the work done today as the foundation for a work plan on activities related to unmet need that clarifies the Committee's responsibilities, planned tasks for the next year, and timeline.

**D. Next Steps**:
- Ms. McKay agreed to draft the summaries of the unmet need activities for these minutes.
- The Committees will build on today's work during subsequent meetings.
- The Executive Committee and full Commission will monitor and ensure coordination of work on unmet need.

**18**. **SUMMARY**:

**A. Summing Up**:
- Ms. McKay said that the Commission clearly recognizes its legislative and ethical responsibility to do all it can to ensure that everyone with HIV/AIDS in the EMA has access to high quality care, and also recognizes the challenges involved.
- Information about unmet need must be used by the Committees and the Commission as a whole in decision-making about where the Commission directs its funding and about system of care.
- Assessing and addressing unmet need is an ongoing, long-term role for the Commission, as well as OAPP.
- Addressing unmet need is challenging because it will create an increased demand for services, will possibly alter service priorities and allocations, and probably changes the continuum of care. In a time of flat or reduced funding, this means difficult decisions. However, addressing unmet need also means that people will live longer and healthier lives.

**B. Session Assessment**: Participants were asked to complete a brief, five-question assessment of the session. Ms. McKay promised to provide a summary of the assessment results.

**C. Closing**: All applauded Ms. McKay for her work. Mr. Braswell thanked all for their attendance and contributions, and staff for their support.

**19**. **PUBLIC/COMMISSION COMMENT, NON-AGENDIZED**: There were no additional comments.

**20. ANNOUNCEMENTS**:
- Mr. Vincent-Jones called attention to an OAPP-hosted public education forum and panel discussion on "State of an Epidemic: African-Americans and HIV", noting that due to demand the participant list was closed, but others were going on the waiting list.
- There is also an application for the California HIV Planning Group, the State's HIV planning council that parallels the Commission.

**21. ADJOURNMENT**: Mr. Braswell adjourned the meeting at 4:40 p.m.

**A. Roll Call**: End-of-the meeting roll call was taken.

| MOTION AND VOTING SUMMARY | | |
|---|---|---|
| **MOTION #1**: Approve the Agenda Order with adjustment. | ***Passed by Consensus*** | **MOTION PASSED** |
| **MOTION #2**: Nomination of Diane Baumbauer to the Title IV seat and James Smith to the Alternate, SPA #1 Unaffiliated Consumer seat for appointment by the Board of Supervisors. | ***Passed by Consensus*** | **MOTION PASSED** |
| **MOTION #3**: Approve the Case Management, Home-Based standards of care, as presented. | ***Passed by Consensus*** | **MOTION PASSED** |